DOCUMENT RESUME

ED 169 946 IR 007 233

AUTHOR Phinney, Joanna; And Others
TITLE I'll Dance At Your Wedding. The Handicapped Child: A Child First. Student Guide--Footsteps. Report Number 20.
INSTITUTION Applied Management Sciences, Inc., Silver Spring, Md.; Educational Film Center, Springfield, Va.; Maryland Univ., College Park. Inst. for Child Study.
SPONS AGENCY Bureau of School Systems (DHEW/OE), Washington, D.C.
PUB DATE 79
NOTE 17p.; For related documents, see IR 007 212-233 and IR 007 396; Best copy available
AVAILABLE FROM University Park Press, 233 East Redwood Street, Baltimore, Maryland 21202 (Student Guide Kit, one of each program, 1-20, $5.95 per kit); Reference Section, National Audiovisual Center, General Services Administration, Washington, D.C. 20409 (Films and tapes only)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS *Child Development; Childhood Needs; Child Rearing; *Early Childhood; *Educational Television; Family Life Education; *Handicapped Children; Parent Child Relationship; Parent Education; *Parenthood Education; *Self Esteem

ABSTRACT

This student guide for a program concerned with the way handicapped children feel about themselves and the way others respond to them provides a brief introduction to the kinds of handicapping conditions, sources of help for handicapped children and their families, and suggestions for ways that parents can meet the special challenge of raising a handicapped child. Designed around a magazine format to allow maximum flexibility to different groups using the materials, the guide is divided into seven sections: (1) an overview of the theme and contents; (2) a summary of the major learnings of the theme; (3) feature articles containing the major content and including practical suggestions for parents; (4) a film review section which includes a synopsis of the accompanying film program and a related discussion question; (5) three activities aimed at both individual and group participation; (6) a selection of field activities, discussion questions, and research topics designed to reinforce the ideas presented in the articles and meet the needs of a wide variety of classroom groups; and (7) a bibliography for further reading on the theme. (Author/JEG)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

THE HANDICAPPED CHILD: A CHILD FIRST

ED169946

U.S. DEPARTMENT OF HEALTH
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

I'll Dance At Your Wedding

A world to be born under your footsteps...
St.-John Perse

FROM THE EDITORS

All parents want the best of life for their children. It is a painful shock, then, when parents discover that their child has a handicap. Many parents learn, however, that a handicapped child can usually lead a full life. They often find that their own lives are enriched by the experience of raising a handicapped child.

This booklet gives a brief introduction to the kinds of handicapping conditions and the sources of help for handicapped children and their families. You'll learn that the way handicapped children feel about themselves and the way others respond to them helps to determine how fully these children develop. You'll also find out ways that parents can meet the special challenge of raising a handicapped child.

CONTENTS

The Big Ideas 2
A Handicap: It's How You Look at It 3
A Special Challenge 6
Form Review Section 9
Activity Pages 10
Great Books 13
Books Cited 14

THE BIG IDEAS

The child who has a handicap can usually lead a full life.

The parents of a handicapped child are most helpful when they accept the child's limitations but give him or her every opportunity to grow.

The challenge of raising a handicapped child can broaden and enrich the parents' lives.

. . . the vulnerable child
—Lois B. Murphy and
Ethel M. Leeper

A HANDICAP:

It's How You Look at It

At the playground, Jamie whispered to his best friend, Sam: "Let's get the wagon."

Sam got the wagon. "OK, Jamie, get in." Jamie grinned. "OK. Help me with my brace."

Sam and Jamie unlocked the brace on Jamie's leg and Jamie sat down in the wagon. Sam pulled Jamie and both boys made engine noises . . .

In the sandbox on the same playground, Carol shoveled sand into a pail. She used her "good" hand and hid the other in her sleeve.

When Carol was very young, she lost a finger in the car door. Neither she nor her parents could adjust to the loss. Now, she never lets others see that hand. And she rarely plays with other children.

How do you separate being "normal" from having special needs?

It's hard. Often there's no clear dividing line between the two. Carol and Jamie, like most handicapped children, are "normal" in many ways. They like wagons and sand. They cry when they fall. They feel happy when someone hugs them. They are more like other children than different from them. Like other handicapped children, however, they have some physical, emotional or mental problem that will affect the course of their lives.

FEELINGS MAKE THE DIFFERENCE

The way a parent helps a child to live with the handicap is very important.

> Except for the few profoundly handicapped children, the handicap is not as important as the way children feel about themselves and the way others respond to them.

For example, Jamie's disability does not hold him back. He accepts his problem and works around it. So does his friend.

Carol and her parents, on the other hand, have let a very small handicap become a real problem. It affects the way she acts with other people and how she feels about herself.

The parents' attitudes toward the handicap are the key to the way their child develops.

WHAT IS A HANDICAP?

Here are some of the problems handicapped children may have:

Some handicapped children see nothing at all.

Some see very poorly, even with thick glasses.

Some cannot hear at all.

Some have partial hearing.

Some children suffer from poor health caused by a disease such as cancer or a defect such as a faulty valve in the heart.

A defect in the bones or nervous system may prevent some children from gaining full control of part or all of their bodies.

Some children have speech impairments; they have difficulty speaking.

It is difficult for some children to listen, think, talk or use symbols because their brains and central nervous systems are not operating in the normal way.

Some children suffer from emotional problems. They may feel very insecure, guilty, or afraid most of the time. They may live in an imaginary world, ignore or shy away from other people.

Some children are born handicapped. Others become handicapped later on through disease or an accident. They may have handicaps that range from mild, to moderate, to severe, to profound. A profound handicap, the most serious impairment, has the most drastic impact on their development. Although all these children have special needs, they do not need the same kinds of services. One may wear a hearing aid and need no other services. Another may need a complete range of services such as physical and speech therapy.

THE SHOCK

Long before the baby is born, parents invest their dreams and hopes in the coming child. This is a time of dreaming and looking forward.

When parents are told their child has a handicap, it's bound to be a shock. Suddenly they feel different — set apart from other people:

Chris: I kept asking myself — why me? It didn't seem fair. All of us — me, my wife, our children, even our own parents were affected by Sarah's handicap.

Jean: When Danny was born and we learned about his problem, I kept going over and over what I did — or didn't do — during my pregnancy to cause his handicap. I wished I'd eaten more nutritious foods. I blamed myself for moving those heavy boxes. I was angry for letting myself get tired and sick the third month of pregnancy. I felt terribly guilty.

Bob: I wondered if I was at fault. Did my genes cause the disability? I began to worry about having a second child...

Nancy: When I was growing up, I hardly ever saw any handicapped people. Even as an adult, I knew no handicapped adults or parents of handicapped children. And now I had a handicapped child of my own. I didn't know what to do. I was afraid to bring Eric out in public for fear everyone would gawk and stare. So I stayed at home. This made me even more lonely and depressed. It began to tear apart our marriage and family life. Fortunately, when we met other parents of handicapped children, I got the support and confidence I needed. And I became my old self once again.

Stan: It was a relief to find out why Peter was so different from all our other children, but the diagnosis made me more afraid. His behavior was not just another "stage." The future was so uncertain. Could we pay additional medical bills? We spent so much time taking Peter to doctors and special programs. Would our lives ever be "normal" again? Would Peter go to school and someday live on his own? Or would I be taking care of him forever? What if I died? My responsibility made me panic.

Most parents of handicapped children have some of these feelings. One of their first tasks is to accept these painful feelings as normal and try to work through them.

MUTTERINGS OVER THE CRIB OF A DEAF CHILD

"How will he hear the bell at school
Arrange the broken afternoon,
And know to run across the cool
Grasses where the starlings cry,
Or understand the day is gone?"

Well, someone lifting cautious brows
Will take the measure of the clock.
And he will see the birchen boughs
Outside the sagging dark from the sky,
And the shade crawling upon the rock.

"And how will he know to rise at morning?
His mother has other sons to waken,
She has the stove she must build to burning
Before the coals of the night-time die,
And he never stirs when he is shaken."

I take it the air affects the skin,
And you remember, when you were young,
Sometimes you could feel the dawn begin,
And the fire would call you, by and by,
Out of the bed and bring you along.

"Well, good enough. To serve his needs
All kinds of arrangements can be made.
But what will you do if his finger bleeds?
Or a bobwhite whistles invisibly
And flutes like an angel off the shade?"

He will learn pain. And, as for the bird,
It is always darkening when that comes out
I will putter as though I had not heard,
And lift him into my arms and sing
Whether he hears my song or not.

The Green Wall
James Wright
New Haven, Conn.:
Yale University Press, 1957.

Copyright © 1957 by James Wright. Reprinted from *Collected Poems* by permission of Wesleyan University Press.

A Special Challenge

Time passes. The parents continue to care for the children, buy the food, and clean the house. They cope. The handicap does not go away, however.

At some point, many parents learn that their *own attitudes* will make raising a handicapped child a devastating experience or a rewarding challenge. They begin to rethink their assumptions about handicapped people. They reevaluate what is important in life. They become able to look at the handicapped child's total growth and special gifts. And they figure out ways to meet the needs of both the handicapped child and other family members.

In other words, they accept the child's handicap. It isn't easy. It doesn't happen all at once. They never stop adjusting to the special problems that the child's handicap creates. They never stop changing or growing.

If parents suspect they have a handicapped child, there are several steps they can take to develop this positive and courageous approach to raising a child who has special needs:

IF PARENTS SUSPECT THAT THEIR CHILD HAS A HANDICAP, THEY SHOULD GET A DIAGNOSIS FROM A DOCTOR OR OTHER PROFESSIONAL AS SOON AS POSSIBLE.

Early detection of a problem can help parents understand their child's needs and get special help. For instance, a child with a hearing loss may be fitted for a hearing aid. This may prevent language or behavior problems that sometimes result when a child can't hear.

SEEK OUT SUPPORT GROUPS AND PROFESSIONAL ORGANIZATIONS FOR HANDICAPPED CHILDREN AND THEIR PARENTS.

Long ago, we used to hear stories about children who were hidden away because of handicaps. Fortunately, all this has changed. Today, handicapped children and their families have many sources of help:

Federal, state and local governments

Congress has recently passed laws to help give handicapped children educational opportunities equal to those for non-handicapped children. Now, all states are working hard to help local school districts meet this requirement.

Services are also provided by local social service organizations and health departments.

Private organizations

There are organizations that give parents information about a particular type of handicap and the kinds of services available in different parts of the country.

Friends, counselors and parents of handicapped children

These people can provide comfort, understanding and support as parents learn to accept their child's handicap and figure out ways for themselves and the entire family to meet the challenges before them.

TRY TO BE REALISTIC ABOUT THE CHILD'S HANDICAP BUT PROVIDE ALL THE OPPORTUNITIES FOR GROWTH THAT EVERY CHILD NEEDS

It's important to be honest with the child and other people about the child's handicap.

"Yes, Sarah does talk differently than you do. It's harder for her to move the muscles in her lips and tongue than it is for you and me. But it's OK to be different. Everybody is."

But remember to notice the child's strengths as well as weaknesses. Sarah, for example, may not express herself well with words She may, however, draw with skill or handle pets with unusual gentleness.

The handicapped child needs the same opportunities to grow as a non-handicapped child — a chance to develop muscles, get along with other people, deal with feelings, learn to think. A child with mental retardation, for example, needs a ride on a swing, children to play with, blocks to build with, and a trip to the fire station — as well as special help. A variety of experiences allows the child to develop.

TREAT THE HANDICAPPED CHILD AS AN EQUAL MEMBER OF THE FAMILY.

Parents can set expectations and limits for the handicapped child just as they do for other members of the family. Every person in the family is capable of doing some kind of job — whether it's sponging off the table or helping to cook the meals.

Rules of behavior such as "no hitting" or "bedtimes" can apply to all. Each child, however, may require different supervision or help. Tommy, an emotionally disturbed child, needs help when he becomes frustrated or angry. At those times his parents stand near to help him find words to express his anger or a space in which to run off his frustration.

LOOKING FORWARD

What can a parent hope for a handicapped child? A few profoundly handicapped children will need supervision or physical care all of their lives. But most handicapped children will be able to enjoy the full range of life's activities -- including a job, marriage, and children.

Whatever the handicap, though, the child needs opportunities to grow and become — just like any child.

Once there was a king who had a beautiful, large pure diamond. There was no other diamond like it in the world. But one day, it became deeply scratched. The king called his best diamond cutters. "I'll promise you a great reward if you can remove the imperfection from my jewel." But they could not. The king was very upset.

Many months later, a man came to the king. He promised to make the diamond even more beautiful than it ever had been. Impressed by the man's confidence, the king consented. He watched as the man engraved an exquisite rosebud around the blemish and used the scratch to make its stem.

— A parable of the Preacher of Dubno from Jewish folklore.

FILM
REVIEW
SECTION

I'll Dance At Your Wedding

Laura and Hunter Riley discover that Cameron, their baby, has a hearing loss. A hearing aid has been prescribed, but both parents are worried that Cameron will never learn to communicate with others. Laura feels very depressed and self-conscious about Cameron's handicap. Hunter thinks that she is overprotecting Cameron. He also feels ignored by Laura and cut off from other people. He convinces her to bring Cameron to a friend's wedding. There they meet Mark, a deaf teenager who plays baseball. They talk to his parents. This experience is a turning point in their and Cameron's lives.

WHAT DO LAURA AND HUNTER LEARN AT THE WEDDING?

ACTIVITY PAGES

activity #1
CONFRONTING YOUR FEELINGS

Describe how you feel when a blind person enters a room, stands next to you on the street corner, or sits next to you on the bus.

What do you do?

What do you feel you should do?

Do you act differently towards this person than you would towards a non-handicapped person?

activity #2
MEETING THE FAMILY'S NEEDS

You are a social worker who visits families in their homes, the hospital, or your office. Your job is to help parents find ways to meet the special needs of their children and, when necessary, refer them to other professionals. In the following situations, discuss what you think the problem might be and what you could do or say to help the parents. As you give your advice, try to keep in mind the big ideas in the previous articles.

1. Marcia has two children, an 8-year-old and a 5-year-old. Tony, the youngest, has polio, a crippling disease rarely seen now since people can be inoculated to prevent it.

   When you arrive, Tom, the older child, is in a bad mood. Tony has just helped himself to another snack and announced that he's going to watch TV after supper. *"It isn't fair,* says Tom. *"Tony gets to watch TV and eat snacks whenever he wants. But I can't eat till supper and I have to do my homework instead of watching TV."*

   Marcia tells him, *"Listen, Tom. Tony can't walk like you and ride a bike like you. You've got to be patient with him. Tony is just different. So he needs different things."*

2. The hospital calls to tell you that another couple, Ed and Mary, have just delivered their first child. Their baby has Down Syndrome (formerly known as Mongolism), a handicapping condition involving mental retardation. It is caused by a genetic defect.

   You are asked to visit Ed and Mary right away. When you arrive at the hospital, both parents seem in a state of shock.

3. Phillip asks you to visit his home. He and his wife, Kathy, disagree about whether Chris, their 4-year-old son, has a problem. You ask what the problem seems to be.

   Philip says, *"Well, it's a lot of things. The main thing is that Chris seems to avoid us. He never looks at me. He shrinks back and licks his hands whenever I try to hug him."*

   "Maybe this is just a stage he is going through," reassures Kathy, *"and he'll grow out of it."*

   "Somehow Chris is really different. Our other kids avoid us occasionally when they're mad — but not like Chris. Not all the time. All our other kids liked to knock down towers, but they didn't build the exact same four-block towers every time and build them up, knock them down in the exact same way for hours. They discovered new things with the blocks," says Phillip.

4. You learn that Sandra can't decide whether to accept an invitation to a birthday party for her daughter, Kara. Kara has been blind from birth. On the one hand, Sandra welcomes the idea of taking Kara to the party because Sandra would love a few moments to herself. On the other hand, Sandra fears that Kara may not benefit from the party. Other children there might make fun of Kara because they have never seen a blind child and are not used to some of her unusual habits.

activity #3
HEALING THE WOUND

Imagine that you have a 5-year-old child with cerebral palsy. Because of his handicap, your child lacks control over many muscles in his body. Over the years he has made tremendous progress, depsite his handicapping condition. Now he is as independent as any 5-year-old. He walks, dresses himself (though slowly) and feeds himself. He's even begun to read! But he has a jerky, somewhat spastic walk and he sometimes grimaces as he talks.

He has just begun regular kindergarten in public school. One day he comes home and bursts into tears. *"Somebody made fun of me. He said I was stupid. He said I walk funny."*

WHAT WOULD YOU DO?

GRAB BAG

to do

1. Invite siblings and parents of handicapped children to your classroom to talk about the following:

   their feelings when they found out their child, brother or sister was handicapped
   the kinds of assistance that the family and handicapped child have received
   how the handicapped child is treated compared to the other children
   how the experience of having a handicapped child has affected them and other members of the family
   how people outside the family have treated the handicapped child and how they wish people would act toward the child
   their hopes for the handicapped child's future.

2. Visit a day care center, Head Start center, nursery school or parent cooperative that has both handicapped and non-handicapped children. Observe a handicapped and a non-handicapped child playing in the same area of the room. Take notes on how these two children are similar or different in their:

   physical coordination
   language ability
   interest in other children and adults
   skill in playing with other children
   enjoyment of play
   ability to solve problems, pretend and create.

   Over all, do you think there are more similarities or differences between these two children? Write a short paper explaining your view.
3. Borrow a wheelchair for half a day. Go everywhere in it — to classes, to the drinking fountain, to the bathroom, in and out of the front door of school. Afterwards, describe how it felt to be unable to walk. What special problems did you have? How did other people react to you? How did you want them to react when they saw you?
4. Watch the same TV show a friend watches, but turn your sound off so that you cannot hear. Both of you should keep notes on what is happening while you watch. Afterwards, compare notes. Were you able to tell what was going on? How did you do it? How did it feel to be unable to hear? Do you think that TV networks should do anything special to help deaf or hearing-impaired people benefit from TV?

to discuss

1. How does society benefit from having handicapped people?
2. Why has there been prejudice against handicapped people in the past?
3. There are more handicapped persons today than in the past. How do you account for this?

GRAB BAG

to research

1. Handicapped individuals who have led full and productive lives. Some people you might research are:

   Jan, a child with Down's Syndrome. See *A Special Gift — The Story of Jan,* by T. deVries-Kruyt.
   Helen Keller, a deaf and blind writer. See *The Story of My Life,* her autobiography.
   Harold Krents, a blind lawyer. See *To Race The Wind,* his autobiography.
   Rogers Meyers, a mentally retarded person in the restaurant business. See *Like Normal People,* his biography.
   Robert Russell, a blind man. See *To Catch An Angel,* his autobiography.
   Jill Kinmont, a physically handicapped teacher. See *The Other Side of the Mountain,* by E. G. Valens.
   Stevie Wonder, a blind musician. See *Stevie Wonder,* by Crescent Dragonwagon.

2. How people's lives have been affected by a handicapped person. Some books that might help you in your research are:

   A Place for Noah, by Josh Greenfield, father of an autistic child.
   Karen, by Marie Killilea, mother of a girl with cerebral palsy.
   Sonrise, by B. N. Kaufman, father of an autistic child.

3. Organizations that are available to aid handicapped persons and their families in your area and across the country. Find out whom they serve and what their services include.
4. One handicapping condition. Look for causes of the handicap, a description of the problem, treatment for it, outlook for a child with the handicap, services and organizations available for help.

BOOK BROWSING

Here are some books that contain more information on...

...handicapping conditions

Help for the Handicapped Child. Florence Weiner. New York: McGraw-Hill Book Company, 1973.

Birth Defects and Your Baby. Jessyca Russel Gaver. New York: Lancer Books, Inc., 1972.

Behavior of Exceptional Children. Norris G. Haring. Columbus, Ohio: Charles E. Merrill Publishing Company, 1974.

...the handicapped child's needs

Infants and Mothers. T. Berry Brazelton, M.D. New York: Dell Publishing Company, Inc., 1969.

Listen to Your Heart. E. H. Wentworth. Boston: Houghton Mifflin Company, 1974.

Preschool Programming of Children With Disabilities. Roger Reger, ed. Springfield, Illinois: Charles C Thomas, 1970.

A Sympathetic Understanding of the Child: Birth to Sixteen. David Elkind. Boston: Allyn I. Bacon, Inc., 1974.

...sources of help

Closer Look information packets: *Practical Advice to Parents; Know Your Rights;* and *Report from Closer Look.* All *Closer Look* materials are FREE from: Closer Look, Box 1492, Washington, D.C. 20013.

CREDITS

Curriculum Development
PRIMARY AUTHOR: Joanna Phinney, Ed.M.
CONTRIBUTING AUTHORS: Sharon Barry, Ed.M.
Laura Dittmann, Ph.D.
Robert Huebner, Ph.D.
Suzanne Thouvenelle, Ed.D.

Content Development
DIRECTORS: Laura Colker, M.A.
Charles Flatter, Ed.D.
TECHNICAL CONSULTANTS: Laura Dittmann, Ph.D.
Robert Huebner, Ph.D.
John Kurtz, Ph.D.
Bonnie Tyler, Ph.D.
Martin Bloom, M.A.

Design & Illustration Sheila Humphreys

FOOTSTEPS was developed by a consortium of:

Applied Management Sciences
Silver Spring, Maryland

Educational Film Center
Springfield, Virginia

Institute for Child Study of the University of Maryland
College Park, Maryland

ACKNOWLEDGMENTS
Many people — staff, students, teachers and parents — contributed to the development of these materials. Two people in particular, however, deserve special recognition and thanks: Sharon McIntyre, for her tireless efforts field testing the materials; and June Hamning, for patiently typing — and retyping — these pages.

We also wish to gratefully acknowledge the ongoing support of the Division of Educational Technology, U.S. Office of Education, without whose assistance these materials would not be possible.

© 1979 Applied Management Sciences

Published by

University Park Press
International Publishers in Science, Medicine, and Education
233 East Redwood Street
Baltimore, Maryland 21202

Copyright is claimed until 1984. Thereafter all portions of this work covered by this copyright will be in the public domain. During the period of copyright all rights, including that of translation into other languages, reserved. Photomechanical reproduction (photocopy, microcopy) of this book or parts thereof without special permission of the publisher is prohibited.

This work was developed under a contract with the Bureau of Elementary and Secondary Education, the United States Office of Education, Department of Health, Education and Welfare. However, the content does not necessarily reflect the position or policy of that Agency, and no official endorsement of these materials should be inferred.